
Post-Breast Cancer Lymphedema and the Family: A Qualitative Investigation of Families Coping With Chronic Illness

M. Elise Radina, M.S., C.F.L.E.

University of Missouri-Columbia

Jane M. Armer, Ph.D., R.N.C.

Sinclair School of Nursing

The number of women who experience breast cancer is increasing. Meanwhile there have been improvements in technologies used for detection and intervention. As a result, more women are living as breast cancer survivors who are now dealing with issues of quality of life related to the aftereffects of treatments. For about one third of women who have treatments involving the removal of and/or irradiation of the axillary lymph nodes, secondary lymphedema of the arm is likely to develop. We take a qualitative approach to investigating how lymphedema affects these women and their families in terms of task completion and family functioning. The Family Adjustment and Adaptation Response (FAAR) Model is used to interpret findings. These indicate that families who are more flexible in modifying daily tasks and who have pre-existing resources for coping with stressors have more positive outcomes than do those families who are rigid and cope with stressors poorly.

Each year, the number of women who experience breast cancer is increasing. More than 180,000 women are affected by breast cancer every year (American Cancer Society, 2000). Along with this increase has been an improvement in the technologies used for detection and

Address all correspondence to M. Elise Radina, Department of Human Development and Family Studies, University of Missouri-Columbia, 314 Gentry Hall, Columbia, Missouri 65211; e-mail: mer6c3@mizzou.edu

JOURNAL OF FAMILY NURSING, 2001, 7(3), 281-299
© 2001 Sage Publications

intervention that has created a decline in the mortality rate associated with breast cancer (Chu et al., 1996). No longer does the discovery of breast cancer equal a death sentence. Instead, more and more women are living as breast cancer survivors. This growing population of women is now dealing with issues of quality of life related to the after-effects of treatments (Ganz, 1999). Increased attention needs to be focused on understanding how these women's post-breast cancer experiences are affecting their daily lives.

There are many treatment options related to breast cancer, including total and partial mastectomies that involve the removal of and/or irradiation of the axillary lymph nodes (Ganz, 1999). For about one third of women who have these lymph nodes removed, secondary lymphedema (hereafter simply referred to as lymphedema) of the arm is likely to develop to some degree at any point during the life span often ranging from weeks to years after the diagnosis and treatment of breast cancer. Lymphedema occurs when the lymph nodes under the arm are removed or damaged by surgery, radiation therapy, or infection. This causes a blockage in the transport of lymphatic fluid and results in the buildup of fluid in the surrounding tissue and along the length of the arm (Lockhart, 1999; Passik, Newman, Brennan, & Holland, 1993). Unfortunately, this condition cannot be cured and is only subject to management through a number of moderately successful and labor-intensive methods, including compression sleeves, a special massage known as manual lymph drainage, and less often today, fluid pumps (Carter, 1997; Lockhart, 1999).

Lymphedema is one of the most troublesome and chronic long-term aftereffects of damage to the lymph nodes (Loprinzi et al., 1999) following breast cancer treatment. The swelling in the arm can be painful, restricting arm movement and causing seemingly simple daily activities to sometimes become difficult (Passik, Newman, Brennan, & Tunkel, 1995; Tobin, Lacey, Meyer, & Mortimer, 1993). As a result, the role that women with lymphedema have played in terms of family care and household duties may have to be modified or changed entirely. The purpose of this study is to examine how family functioning is changed by the onset of lymphedema.

Impact on Women

The role that women play within the family is often one of caregiver, schedule keeper, housekeeper, cook, and others related to maintaining family functioning on a day-to-day basis. When not

engaged in these household tasks, many women participate in hobbies that are related to family work, such as gardening, driving children or other family members to and from events, photography, and exploring the Internet. Also, women often combine necessary household work with leisure activities, such as talking on the phone with a friend while cooking and watching children while socializing with neighbors (Hochschild & Machung, 1989; Knox & Schacht, 2000). Some women can be characterized as reluctant to give up the responsibility of family matters and using household work and mothering as a source of external identity (Allen & Hawkins, 1999). This can mean greater perceived independence and therefore a desire to avoid dependence on others for the completion of family and household work.

Most of the activities associated with the role women play within the family require a certain amount of energy and mobility. For women experiencing the debilitating effects of lymphedema, these daily tasks may sometimes become difficult (Carter, 1997; Passik et al., 1995; Tobin et al., 1993). Because these daily activities of the family are often a source of personal identity for women, this study examined what impact the physical inability to complete these tasks means to these women.

A study of mothers with chronic illness revealed that these women experience internal conflicts between the obligation of mothering and the management of their chronic illness. These women are primarily concerned with the ability to perform their role as mothers and their availability to children (Thorne, 1990). From these findings, we would expect that for women confronted with chronic illness, their capacity to continuing their performance of family responsibilities is salient. The present study seeks to understand whether these same concerns are also present for the understudied population of women with the chronic illness of lymphedema.

Impact on Families

Familial response to chronic illness is often best examined using a family systems framework. Within this framework, families are considered to have structure and function. Family structure refers to the boundaries, physical and psychological, that denote who is considered within and apart from the family (Boss, 1993). Family functioning, on the other hand, refers to the interconnected patterns of relationships between family members (Whitchurch & Constantine, 1993).

Family structure and functioning are influenced by and have influence over the family's response to stress. One theoretical model developed from the family systems framework that specifically addresses family response to stress is the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988). This model suggests that as families encounter new demands (stress), the family system works to achieve homeostasis in functioning. It is suggested that families are able to achieve this by developing new ways to cope with stress, reducing the number and magnitude of the stress, and/or changing the way the family views the stress (Patterson & Garwick, 1994). This model of familial response to stress is an important framework with which to examine the impact of stressors, such as a chronic illness, on the family. (See Figures 1 and 2).

When considering the connection between family structure and the family system, the person's relationship with family members needs to be examined. Family structure consists of the physical and psychological boundaries of the family. Chronic illness can cause these boundaries to become ambiguous, as the family member with the chronic illness may be physically present while psychologically absent. Boss (1993) suggested that this ambiguity can compromise family functioning. For example, women who were diagnosed with breast cancer reported negative relationship functioning in their relationships with significant others. This has been attributed to the provision of physical care but an absence of emotional care (Bolger, Foster, Vinokur, & Ng, 1996). Here, the boundary ambiguity created when physical and psychological support were provided influenced relationship functioning.

In their study of family functioning in cases with mother's chronic illness, Lewis, Woods, Hough, and Bensley (1989) found that the mother's illness indeed had a significant impact on the family. Family functioning was found to be negatively affected by the increase in stress related to the demands of the illness. Also, family functioning was negatively impacted by the mother's level of depression, which was triggered by the illness. Lymphedema, also considered a chronic illness, has been found to produce difficulties for women related to the family (Tobin et al., 1993). For example, living with lymphedema is often accompanied by labor-intensive methods currently used for its care (Carter, 1997; Lockhart, 1999) and psychological distress for the individual (Passik et al., 1995). Both of these outcomes can impact the family in terms of additional demands on the family. Therefore, there is reason to believe that family functioning may be adversely

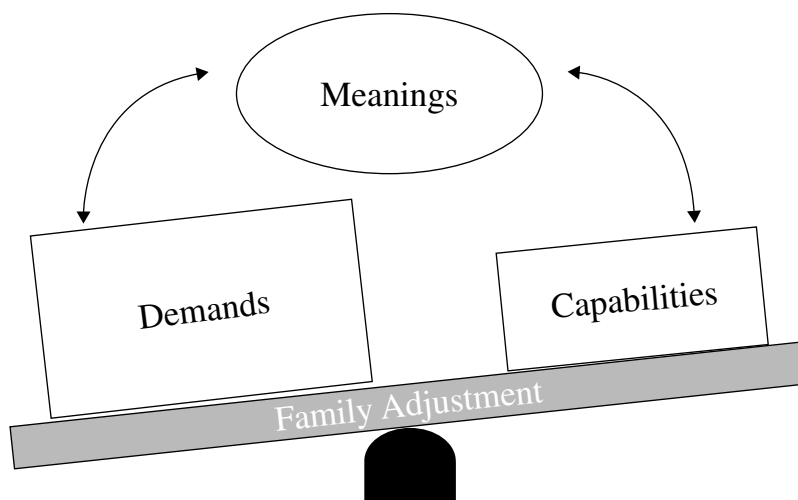


Figure 1: The Family Adjustment and Adaptation Response (FAAR)
Model: Adjustment Phase
Source: Adapted from Patterson (1988).

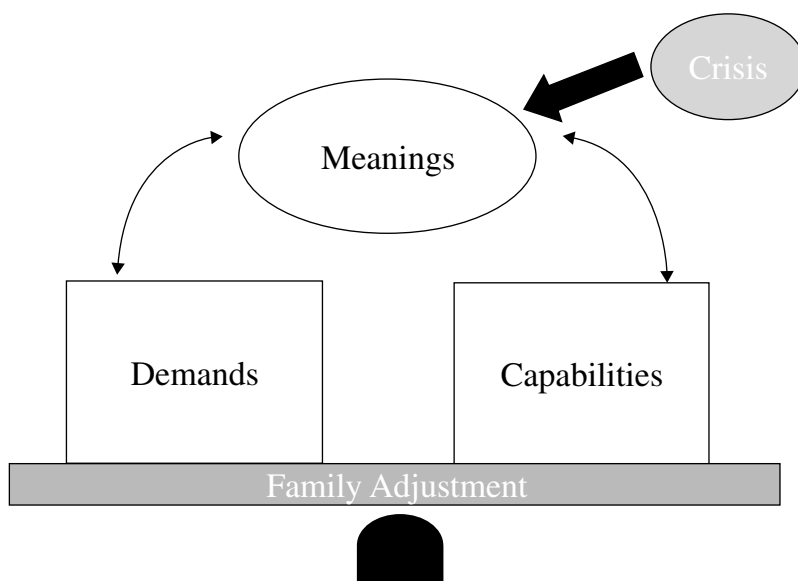


Figure 2: The Family Adjustment and Adaptation Response (FAAR)
Model: Adaptation Phase
Source: Adapted from Patterson (1988).

affected by the presence of lymphedema. These findings suggest that lymphedema, as a chronic illness, is likely to have an impact on family functioning. The present study seeks to understand how lymphedema impacts family functioning related to changes in the demands on the family and family relationships.

The above review of the literature focuses attention on several potential issues for women living with lymphedema. Broadly, the present study seeks to understand whether the concerns for individuals dealing with other chronic illnesses are also present for the understudied population of women living with lymphedema. Specifically, the present study seeks to understand how lymphedema impacts family functioning as a result of changes in demands on the family and family relationships. The literature suggests that family functioning may be adversely affected by the presence of lymphedema. How is family functioning influenced by the onset of lymphedema? Also, what impact will the physical inability to complete these tasks mean to these women? The literature also suggests that lymphedema, as a chronic illness, is likely to have an impact on relationships within the family—especially those within the immediate family and with family members as caregivers. In particular, what will the inability to fulfill this role in the family mean for family functioning and family relationships?

METHOD

Overview

In the present study, the processes and experiences related to living with lymphedema are addressed. In an effort to best capture this lived experience and to understand its meaning in the everyday lives of women living with lymphedema, we chose an ethnographic approach to data collection. Emerson, Fretz, and Shaw (1995) described ethnography as the researchers' participation in a particular sphere that is unfamiliar and the clarification and description of this sphere based on the researchers' participation. At the principal level, we chose to use this definition as our guide in the present study. Also, although we did have certain *a priori* expectations for what we would find based on a review of the literature, we were less interested in testing hypotheses and more interested in understanding the complexities of

living with lymphedema as a chronic illness. Therefore, our approach to this study is appropriate in terms of qualitative philosophy.

To help generate a more clear and well-rounded understanding of this experience, we have chosen a variety of data sources or units of analysis. This approach helped us to achieve two goals. First, this approach allowed us to generate data that could inform our understanding of the role context plays in living with lymphedema (Patterson & Garwick, 1994). Second, the approach allowed us to enter the lives of these women without engaging in full immersion. Some authors argue that full immersion is the only way to conduct ethnographic studies correctly. However, we have chosen to view ethnography as a synthesis of data sources to create a more full understanding of the lived experience. This approach can be considered appropriate in light of the fact that within the social sciences, the use of ethnography is fundamentally diverse (Atkinson & Hammersley, 1998).

Participants

The participants for this study included women with lymphedema who were referred from a variety of settings, including surgical, medical, and radiation oncologists, and were members of a newly forming lymphedema support group in central Missouri. All of the women were over the age of 18 (estimated average age: 45 years), were treated with surgery and/or radiation for breast cancer, and had lymphedema in the affected limb (Armer & Whitman, in press).

Data Collection

Preliminary interviews were conducted with women as part of a larger study entitled "Self-Management of Chronic Illness" (Armer, 1999). These interviews examined perceptions of health, agency in personal health maintenance, changes in lifestyle due to lymphedema, and issues of social support. The purpose of including these data was to provide the primary researcher with entrance into this population of women and to prepare her with background knowledge and understanding of these women's experiences prior to participating in their lives. Follow-up interviews were conducted with six women, some of whom were previously interviewed. These interviews focused specifically on issues related to coping with lymphedema within the

context of family roles and responsibilities and family functioning. Two professionals, an oncology nurse and a physical therapist, who have experience with breast cancer survivors, and women living with lymphedema were interviewed. The purpose of these interviews was to utilize the firsthand professional knowledge these individuals have regarding the everyday challenges and treatment of lymphedema as it relates to the lives of women and their families.

On three occasions, the primary researcher had the opportunity to observe a newly formed lymphedema support group in central Missouri. This experience, having already gained entrance to this population using the above avenues, allowed for observation of the discussions these women shared about their experiences, including those related to daily functioning and family.

Data Analysis

Preliminary interviews were examined for insights related to well-being, roles, tasks, social support, family participation, and relationship issues. The primary researcher's impressions generated from this examination were incorporated into field notes. From the reading of these interviews and the field notes, the issues of family functioning and well-being stood out as salient issues for women living with lymphedema. Follow-up interviews and interviews with professionals addressing these issues were audiotaped, with detailed field notes written following each interview. Observations of the lymphedema support group were also written in detailed field notes following each observation.

Coding began as a line-by-line read through of the data in its entirety as outlined by Emerson et al. (1995). This was followed by open coding resulting in more than 300 specific codes. After completing this stage of coding, the primary researcher completed a series of memos to clarify thoughts about the codes that had been generated and to begin to make connections between them. At this point, the development of larger focused codes consisted of sorting field notes into categories and identifying themes within these categories. These themes were then coded in such a way to reflect the variations within each theme (Emerson et al., 1995).

After the development of focused codes, a detailed summary of these codes was created for use with member checks. These member checks were included to establish credibility for the findings by testing interpretations and conclusions with members of the group being

studied (Lincoln & Guba, 1985). Two women who were members of the lymphedema support group and had not participated in the interviews were invited to participate in this stage of data analysis. Results of these member checks indicated that, with a few minor exceptions, interpretations and conclusions were accurate. These exceptions are noted throughout the results.

RESULTS AND DISCUSSION

From the preceding data analysis, two specific findings related to family functioning and family relationships were generated. These findings address issues of modification of difficult daily activities for these women and their families and women's perceptions of relationships with others both within and outside the family unit.

Finding 1: Because of the impact lymphedema has on daily tasks, many of the women must modify the way these tasks are accomplished by changing the way the task itself is done and/or employing the help of others.

Daily tasks. As suggested by Passik et al. (1995) and Tobin et al. (1993), daily activities, such as household responsibilities and leisure activities, are sometimes difficult for women living with lymphedema and may influence the way women and their families operate to accomplish these tasks. This is especially true for families who choose not to incorporate outside services in the completion of household tasks. Also, as pointed out during member checks, those women who are following guidelines given by their doctors or physical therapists face particular challenges in completing family and household tasks.

There are several possible reasons why daily activities may be difficult for these women to complete alone. First, one of the primary guidelines women with lymphedema are given upon diagnosis is to avoid using the affected arm to lift anything more than 10 pounds. This particular guideline makes activities, such as caring for a young child, grocery shopping, yard work, and some housework, difficult. For example, this could influence daily functioning for women like Sylvia, who was at risk for developing lymphedema following her breast cancer treatment 13 years ago. During that time she was a single mother of two children, a 5-year-old boy and a 6-month-old girl. She says,

Over the last 13 years I have been troubled very little by lymphedema. It is a good thing because I had a lot of physical demands in taking care of my family including a small child. If I had to avoid lifting 10 pounds, it would have been hard.

Women with lymphedema are also told to reduce the amount of repetitive movement they subject the affected arm to on a regular basis. This can compromise one's ability to participate in tasks like cleaning, painting, or working at a computer. Lynn, who has been living with lymphedema for 5 years, says,

I used to get on all fours and clean the kitchen floor by hand. Now I use a sponge mop because I can't do it the way I used to. My husband vacuums and cleans the bathroom because these are repetitive motions. I am usually able to do the rest of the cleaning myself.

Mobility with the arm is also compromised because of arm size due to swelling, pain, or treatments. In terms of treatment, the arm is initially wrapped in up to eight layers of bandages to reduce swelling. These bandages make use of the arm difficult because the mobility of the elbow is reduced and the bandages must be kept dry. After sufficient reduction is achieved, women are then fitted for a compression garment that extends the length of the arm and is designed to maintain pressure and proper lymphatic flow. A glove is also worn to maintain pressure on the hand. For Marcia, these treatments made parenting her toddler difficult,

Giving my daughter, Anne, a bath was hard. It wasn't that I was not capable, it was just a huge production to remove eight layers of bandages, roll them up, and rewrap my arm. It's time consuming. Also, doing Anne's hair is difficult because of the glove [which she now wears with the compression garment]. It catches on her hair and makes it harder for me to grip her hair tightly.

Task modification. For many of the women we interviewed, modification was often the key to completing tasks while following the guidelines and dealing with treatments. Kay, a physical therapist, explained that these women's responsibilities at work and at home have not really changed as a result of the onset of lymphedema. She suggests that it simply may take a few more minutes to do things. She tells her patients, "Go, be a normal woman." Judy, who has been liv-

ing with lymphedema for the past 2 years, echoes this sentiment by saying, "You just have to adapt and figure out how to do things differently."

There are two primary reasons why women living with lymphedema and their families must modify the way tasks are completed. First, to prevent an increase in swelling, many women follow the guidelines described above. In addition to restrictions on lifting and repetitive motions, women are also told to avoid sunburns and insect bites that may lead to infection. This may limit opportunities for these women to participate in outdoor activities with their families. For example, Judy has enjoyed participating in yard work with her family. Now, she must either refrain from participating or take several precautions to protect herself. Specifically, Judy uses industrial insect repellent on her skin and clothing and wears clothing that covers all exposed areas to avoid sunburns and insect bites. Even enjoying her son's soccer game on a spring afternoon is difficult and uncomfortable because of all of the precautions she needs to take.

Kay, a physical therapist, impresses all of these guidelines upon her patients. She tells them to wear gloves when gardening or washing dishes, wear extra sunscreen, avoid lifting, and avoid lengthy repetitive motions with the arm, such as vacuuming and painting. Kay advocates making adjustments to tasks rather than avoiding them entirely. For example, she recommends switching arms when repetitive motions are necessary.

Beyond the advice given by professionals like Kay, some women have discovered their own ways to make modifications. For example, Judy has found ways to avoid lifting while completing these tasks without assistance. Her family has a dog; therefore, when she is grocery shopping, she often buys a large bag of dog food. Rather than carry it herself, she has it loaded into the car and then uses a pushcart once she gets home to move it into the house.

As mentioned above, another reason that women with lymphedema must often modify their activities is because the treatment can make tasks cumbersome to complete. In particular, those activities requiring the delicate use of fingers need to be modified to accommodate the wrapping and/or the compression glove. Judy explained that she used to take her glove off to crochet because wearing it made the activity uncomfortable and slow. Because she experienced swelling in her hand when she took the glove off, she had to learn how to crochet while wearing the glove. Similarly, some women who completed

tasks, like sewing by hand, found that they reluctantly had to adjust to the use of a sewing machine because the glove made sewing small stitches difficult.

The modification of daily tasks by these women and their families can be seen as a resource for family adaptation to chronic illness. Specifically, families who exhibit flexibility have been found to have better outcomes than those families who are more rigid (Watson, Henggeler, & Whelan, 1990). Family flexibility, in this case, refers to the ability to make modifications to daily tasks and routines, such as those described above.

Women's reactions to task modifications. Although daily activities are often difficult for women with lymphedema, many of these women are finding a way to normalize the changes in their lives. They often take a few more minutes to complete tasks or find new ways to do things.

Feeling as though they cannot complete these tasks can, however, be difficult for those women who attribute their identity to them and for whom being independent is especially important. For example, Sylvia resents the fact that she has to be careful with an arm that still has a lot of demands placed on it. Being a single parent, there are many tasks she needs to complete, including yard work, groceries, carrying bags of dog food, painting, and wallpapering. She says, "These are things that I have enjoyed and needed to do." She feels that these are things that defined her capabilities, who she is. Now she must rely on her children for things that she would normally do for herself.

Like Sylvia, Judy feels that having to make modifications has meant giving up her independence and having to rely on others for assistance. For example, Judy has had to ask her husband to do things for her like moving furniture. This is something she used to not have to ask for help with. She says, "I don't like it. I want to do it myself. When you think of something you want to do, you want to do it now and not have to wait for someone else."

Some women who are living with lymphedema become dependent on others to accomplish tasks. This can lead to feelings of losing independence and the identity they found in completing those tasks on their own. This impact of lymphedema can have important repercussions on family functioning. According to the FAAR Model, the meaning the family and the individual attribute to the stressor and

the family's ability to cope with it are important for family functioning. For the women and their families who have to modify the completion of daily tasks, meaning seems to take on particular importance. Reiss, Steinglass, and Howe (1993) suggested that those families who significantly alter or give up family routines are at risk of experiencing imbalanced family functioning. In these cases, women and their families who place too much importance on dealing with lymphedema at the expense of other family needs (e.g., parent-child relationships) may encounter problems with family functioning in the form of reducing personal resources (e.g., self-esteem, sense of mastery) meant to deal with stressors.

Finding 2: Because of the impact lymphedema has on daily tasks, many women and their families must cope with changes brought on by lymphedema in relation to family functioning and family relationships.

The experiences of two particular participants, Marcia and Sally, demonstrate both the negative and positive extremes of family functioning outcomes for families coping with breast cancer in combination with lymphedema. One way to understand these outcomes is to consider the dynamics of these families using the FAAR Model (Patterson, 1988). According to the FAAR Model, families experience repeated cycles of stress. These can be attributed to expected developmental changes (marriage, birth of a child) after which the family adapts and returns to stability. Unexpected stress, such as diagnosis of a chronic illness, causes a crisis in the family until new resources or coping strategies can be found to deal with the stress. The family's ability to adjust to changes often predicts its reaction to unexpected stress (Patterson & Garwick, 1994). Those families faced with chronic stress have been found to either present outcomes of coping very poorly or very well. Marcia's and Sally's stories provide excellent examples of how this is true for women living with lymphedema and their families.

Marcia. Marcia is a divorced, single mother of a 5-year old in her late 40s. Marcia perceives her relationships with others in her life, especially her ex-husband and brother, to be rather negative. She also feels the support she receives from others is insufficient. What support she does receive is limited to occasional physical assistance from her mother and friends. In terms of emotional support, Marcia feels

alone. Marcia is hurt that her brother is not more helpful with the things around the house, like lawn cutting and outdoor maintenance that she cannot do. She says, "It just bothers me that he doesn't even call." She feels he doesn't understand or care about her problems. Marcia also finds her brother to be disloyal and self-centered because he is still friends with her ex-husband, and he has never called to see how she is doing or if she needs anything. During her breast cancer and lymphedema treatment, Marcia recalls that, compared with other women's husbands, "My husband didn't want anything to do with it." She was traveling several hours away from home for treatment of the lymphedema and recalls that her husband was growing more and more distant emotionally. Later, she found out that he was having affairs while she was away. Marcia's feelings about support may be compounded by the recent divorce from her husband. She believes that breast cancer and lymphedema are in large part to blame for the dissolution of their marriage.

In Marcia's case, she and her husband may have experienced years of stress in dealing with other stressors, including her other illnesses (e.g., osteoporosis and Crohn's disease) and raising a small child. The family's inability to adjust to stress can be seen in the increasingly conflictual interaction that Marcia was experiencing with her husband. The added stressor of lymphedema may have pushed Marcia's family beyond its ability to adjust to unexpected stressors. Specifically, Marcia's increasing engagement in seeking education and treatment for breast cancer and lymphedema, marked by her absence from the family unit, may have led to altered family functioning. Perhaps this was exacerbated in this case by the preexisting health conditions (Crohn's disease and osteoporosis) she and her family had already endured. Currently, the people Marcia feels she has negative relationships with are her brother and ex-husband. These feelings may be a result of boundary ambiguity in which her loss is unclear (Boss, 1993). On one hand, Marcia is still psychologically connected to her brother and ex-husband; on the other, their physical presence in her family life is absent.

Sally. Sally is a married mother of three adolescents who is in her mid-50s. Sally feels that her relationship with her husband since diagnosis with lymphedema is even stronger and closer than it was before. It bothers her children that she has a wrapped arm. They show their support by using humor—her sons call her "mummy." Sally is one of eight children. She refers to them as "the Waltons." Her siblings have

been very supportive. For example, they bought Christmas gifts for the children 2 years ago because she and her husband were unable to do it. Her siblings are also planning to pay for whatever the insurance does not cover for the compression sleeve that she should be getting soon. Sally also finds support through her church. She explained that when she was going through the breast cancer treatment (chemotherapy), church members would bring food to the family for a week after every treatment, so the family didn't have to cook or buy groceries. They were totally taken care of. Also, Sally's mother was insistent on being there for a week after each chemotherapy treatment. After chemotherapy, her white count was low, so she was susceptible to infection. Sally's children became very protective of her. She says, "They were like junkyard dogs at the door of our house. They would tell people who came to the door, 'Don't you even breathe in this house.' " Now that she is wrapping, Sally does much of it herself, but if her husband is home, he insists on doing it for her. She says that her husband is very upset about what has happened because, "What happens to me, happens to him." He was there the entire time during the treatment.

For Sally, deeper relationships were formed with her husband and children following diagnosis with lymphedema. One explanation for this outcome using the FAAR Model is that Sally's family already had the capabilities to deal with unexpected stress. Patterson, Budd, Goetz, and Warwick (1993) suggested that family coping in the context of chronic illness consists of three components: (a) maintenance of family solidarity, (b) maintenance of support and self-esteem of family members, and (c) actively seeking medical advice and support. For Sally's family, all of these components were present to help prepare the family for the unexpected stress of lymphedema. First, because Sally homeschooled her children, the foundation had already been laid for family solidarity. Sally and her husband involved their children in Sally's breast cancer and lymphedema experience, thus helping to maintain family solidarity. Second, unlike in Marcia's case, Sally's family members, including parents and siblings, came together as a unit to support each other with coping. Third, Sally is a trained medical researcher and therefore brings her knowledge and curiosity to coping with this unexpected stress. She maintained her own medical records of her diagnosis and treatment and was therefore prepared to actively seek medical advice and support. Family structure and function that was already strong became even stronger during the crisis of coping with lymphedema as a new source of stress.

IMPLICATIONS FOR PRACTITIONERS

As more and more women are living as survivors of breast cancer, issues related to their posttreatment quality of life become more salient. The present study focused on women experiencing the potentially chronic aftereffect of breast cancer treatment known as lymphedema. There seem to be similar concerns among these women as there are for individuals with other chronic illnesses: the obligation of mothering and the management of their chronic illness. For the women who participated in this study, the primary issues they are facing are focused on adjusting the completion of the daily tasks expected of them as mothers and addressing the physical changes and treatments they are experiencing as a result of lymphedema. This adjustment is a result of many factors including impaired arm movement, preventing progression of the lymphedema, and participating in available treatment options. For a number of these women, becoming unable to complete daily tasks independently meant not only that making adjustments was difficult logistically but also difficult emotionally.

Not only are these women adjusting to changes but so too are their families. As these women come to rely on family members for assistance with daily tasks and treatment, the functioning of the family is influenced. Outcomes that reflect more positive than negative family functioning appeared from these data to be a result of greater flexibility within the family, more positive meanings associated with lymphedema, balancing of family and illness needs, and the family's prior ability to cope with additional stressors.

The results of these analyses provide perspective on these lives of women living with lymphedema and their families. Not only do they support the findings of others (e.g., Passik et al., 1995; Patterson & Garwick, 1994; Tobin et al., 1993), but they also raise issues important for practitioners. First, practitioners can help these women and their families to cope with lymphedema by encouraging flexibility rather than rigidity in task modification. Second, practitioners can also encourage families to maintain a balance between usual family needs and the needs of the illness to regain family balance. Last, practitioners need to consider the structure and function of a woman and her family as a unit to help prevent the buildup of stressors following diagnosis and during adjustment to avoid crisis and family imbalance. Specifically, aspects of family structure and function that are strong can perhaps be further strengthened to enable a woman and her family to cope with the enduring stress of secondary lymphedema.

When family structure and function are assessed to be weak prior to the onset of lymphedema, practitioners may need to help women identify secondary support systems, such as lymphedema support groups, other women coping with similar struggles, or referrals to professional counselors who are equipped to help these women cope with the additional stressors brought on by lymphedema.

REFERENCES

- Allen, S. M., & Hawkins, A. J. (1999). Maternal gatekeeping: Mothers' beliefs and behaviors that inhibit greater father involvement in family work. *Journal of Marriage and the Family*, 61, 199-212.
- American Cancer Society (2000). *Cancer facts & figures-1999*. Atlanta, GA: American Cancer Society.
- Armer, J. M. (1999). *Self-management of chronic illness*. Unpublished data, University of Missouri-Columbia.
- Armer, J. M., & Whitman, M. (in press). The problem of lymphedema following breast cancer treatment: Prevalence, symptoms, and management. *Journal of Women and Cancer*.
- Atkinson, P., & Hammersley, M. (1998). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 110-136). Thousand Oaks, CA: Sage.
- Bolger, N., Foster, M., Vinokur, A. D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology*, 70, 283-294.
- Boss, P. G. (1993). The reconstruction of family life with Alzheimer's disease: Generating theory to lower family stress from ambiguous loss. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 163-166). New York: Plenum.
- Carter, B. J. (1997). Women's experiences with lymphedema. *Oncology Nursing Forum*, 24, 875-882.
- Chu, K. C., Tarone, R. E., Kessler, L. G., Ries, L. A., Hankey, B. F., Miller, B. A., & Edwards, B. K. (1996). Recent trends in U.S. breast cancer incidence, survival, and mortality rates. *Journal of the National Cancer Institute*, 88, 1571-1579.
- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes*. Chicago: The University of Chicago Press.
- Ganz, P. A. (1999). The quality of life after breast cancer—Solving the problem of lymphedema. *The New England Journal of Medicine*, 340, 383-385.
- Hochschild, A., & Machung, A. (1989). *The second shift: Working parents and the revolution at home*. New York: Penguin.
- Knox, D., & Schacht, C. (2000). *Choices in relationships: An introduction to marriage and the family*. Belmont, CA: Wadsworth.
- Lewis, F. M., Woods, N. F., Hough, E. E., & Bensley, L. S. (1989). The family functioning with chronic illness in the mother: The spouse's perspective. *Social Science & Medicine*, 29, 1261-1269.

- Lincoln, Y., & Guba, E. (1985). Establishing trustworthiness. In Y. S. Lincoln & E. G. Guba (Eds.), *Naturalistic inquiry* (pp. 289-331). Beverly Hills, CA: Sage.
- Lockhart, J. S. (1999). Commentary: The nurse's role in providing health education about lymphedema. *Oncology Nursing Forum*, 26, 507-509.
- Loprinizi, C. L., Kugler, J. W., Sloan, J. A., Rooke, T. W., Quella, S. K., Novotny, P., Mowat, R. B., Michalak, J. C., Stella, P. J., Levitt, R., Tschetter, L. K., & Windschitl, H. (1999). Lack of effect of coumarin in women with lymphedema after treatment for breast cancer. *The New England Journal of Medicine*, 340, 346-350.
- Passik, S. D., Newman, M. L., Brennan, M., & Holland, J. (1993). Psychiatric consultation of women undergoing rehabilitation for upper-extremity lymphedema following breast cancer treatment. *Psychiatric Consultation of Lymphedema Patients*, 8, 226-233.
- Passik, S. D., Newman, M. L., Brennan, M., & Tunkel, R. (1995). Predictors of psychological distress, sexual dysfunction and physical functioning among women with upper extremity lymphedema related to breast cancer. *Psycho-oncology*, 4, 255-263.
- Patterson, J. M. (1988). Families experiencing stress: The family adjustment and adaptation response model. *Family Systems Medicine*, 5, 202-237.
- Patterson, J. M., Budd, J., Goetz, D., & Warwick, W. (1993). Family correlates of a ten-year pulmonary health trend in cystic fibrosis. *Pediatrics*, 91, 383-389.
- Patterson, J. M., & Garwick, A. W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine*, 16, 131-142.
- Reiss, D., Steinglass, P., & Howe, G. (1993). The family's organization around the illness. In R. Cole & D. Reiss (Eds.), *How do families cope with chronic illness?* (pp. 173-213). Hillsdale, NJ: Lawrence Erlbaum.
- Thorne, S. E. (1990). Mothers with chronic illness: A predicament of social construction. *Health Care for Women International*, 11, 209-221.
- Tobin, M. B., Lacey, H. J., Meyer, L., & Mortimer, P. S. (1993). The psychological morbidity of breast cancer-related arm swelling: Psychological morbidity of lymphedema. *Cancer*, 72, 3248-3252.
- Watson, S. M., Henggeler, S. W., & Whelan, J. P. (1990). Family functioning and the social adaptation of hearing-impaired youths. *Journal of Abnormal Child Psychology*, 18, 143-163.
- Whitchurch, G. G., & Constantine, L. L. (1993). Systems theory. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 325-352). New York: Plenum.

M. Elise Radina is a doctoral candidate, Department of Human Development and Family Studies, University of Missouri-Columbia. She teaches in the areas of adulthood and aging, family life education, and multicultural families. Her research interests include family caregiving and multicultural issues in families. Recent publications include (with T. M. Cooney) "Adjustment Problems in Adolescence: Are Multiracial Children at Risk?" (2000) in *American Journal of Orthopsychiatry*, 70, and (with T. M. Cooney) "Parent-Child Relationship Quality Among Multiracial Adolescents and Their Biological Parents," (2000) in *American Journal of Orthopsychiatry*, 70.

*Jane M. Armer is associate professor, Sinclair School of Nursing, University of Missouri–Columbia, and director of nursing research, Ellis Fischel Cancer Center. She teaches in the areas of nursing research and health promotion and conducts research in chronic illness management, specifically post–breast cancer lymphedema. She is certified in gerontological nursing and as a manual lymph drainage therapist. Recent publications include (with E. J. Porter and L. H. Ganong) “The ‘Church Family’ and Kin: Contrasts in the Service Providers of an Older Rural Black Woman,” (2000) in *Qualitative Health Research*, 10(4), and (with V. Conn) “Spirituality and Health Among Diverse Rural Elders,” (in press) in *Journal of Gerontological Nursing*.*